

Sharing and Integrating HIV Client Data Across Provider Organizations to Improve Service Coordination

A Toolkit

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Preface

Recognizing the potential power of close collaboration, two federal programs that provide support to low-income people with human immunodeficiency virus (HIV)—the Housing Opportunities for Persons With AIDS program of the U.S. Department of Housing and Urban Development and the Ryan White HIV/AIDS Program, overseen by the Health Resources and Services Administration (HRSA)—came together to determine how they could improve outcomes for individuals with HIV who also experience housing instability. The result of that meeting was an effort to encourage more-effective data-sharing and coordination of services across the two programs. This data integration project was carried out with four local partnerships and evaluated by the RAND Corporation. As part of the evaluation, we developed this toolkit as a way to share lessons learned and help others who are considering similar efforts to share data across service providers.

This research was supported by HRSA and the Minority HIV/AIDS Fund of the U.S. Department of Health and Human Services (HHS) under grant number U1SHA29299 *Addressing HIV Care and Housing Coordination Through Data Integration to Improve Health Outcomes Along the HIV Care Continuum*, with total funding of \$3,559,101. This information or content and conclusions are those of the author and should not be construed as the official position or policy of, nor should any endorsements be inferred by HRSA, HHS, or the U.S. Government.

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Abbreviations

AIDS	acquired immune deficiency syndrome
HHS	U.S. Department of Health and Human Services
HIPAA	Health Insurance Portability and Accountability Act
HIV	human immunodeficiency virus
HOPWA	Housing Opportunities for Persons With AIDS
HRSA	Health Resources and Services Administration
HUD	U.S. Department of Housing and Urban Development
RWHAP	Ryan White HIV/AIDS Program

1. Introduction

The social determinants of health—that is, the conditions in which we live, work, and play—explain our health outcomes to a large extent. Opportunities to live in health-promoting environments affect our ability to eat well, exercise, and enjoy an enhanced quality of life, and this is no different for people with human immunodeficiency virus (HIV). Research has shown that housing is one of the most significant social determinants of HIV-related medical outcomes, because poor housing is associated with lower levels of access to medical care and lower antiretroviral treatment (use and adherence). Poor housing also presents competing survival needs that supplant demands related to health care (Aidala, Cross, et al., 2005; Aidala, Lee, et al., 2007; Aidala, Wilson, et al., 2016; Cornelius et al., 2017; Gallagher et al., 1997; Gelberg et al., 1997; Harris, Xue, and Selwyn, 2017; Kidder et al., 2007; and Moss et al., 2004).

Given the extent to which homelessness and housing instability overlap with the HIV epidemic, better coordination of housing and medical services for people with HIV in compromised housing situations could be one way to improve health outcomes. Good service coordination across providers relies on effective sharing of client data. In the absence of integrated data systems that can automatically and securely share client data, providers spend additional time making phone calls, writing emails, and conducting other administrative tasks to secure client documentation. This can lead to inefficiencies and, potentially, missed opportunities to talk to clients with all critical information available.

Officials with the two federal programs sought to address this situation for their overlapping clients: the Housing Opportunities for Persons With AIDS (HOPWA) program, located in the U.S. Department of Housing and Urban Development (HUD); and the Ryan White HIV/AIDS Program (RWHAP), overseen by the Health Resources and Services Administration (HRSA). HUD and HRSA set a mutual goal to improve local service coordination across HOPWA and RWHAP programs (U.S. Department of Health and Human Services and U.S. Department of Housing and Urban Development, 2017).

From 2015 to 2019, HRSA, in collaboration with HUD’s Office of HIV/AIDS Housing, funded a project entitled *Addressing HIV Care and Housing Coordination Through Data Integration to Improve Health Outcomes Along the HIV Care Continuum* (HRSA, 2019). This project was designed to test how the effects of integrating housing and medical data affected provider utilization of data systems, coordination of housing and HIV care services, and, ultimately, the effect on client health outcomes along the HIV care continuum (i.e., the steps that a person with HIV takes from initial diagnosis to achieving viral suppression). The RAND Corporation served as the Coordination and Technical Assistance Center, conducting a multisite demonstration and evaluation and providing implementation technical assistance to performance sites. The performance sites were the

- Department of Health and Human Services, Hartford, Connecticut
- Cascade AIDS Project, Multnomah County, Oregon
- Department of Health, City of Kansas City, Missouri
- Department of Community Services, Palm Beach County, Florida.

Based on the experiences and findings resulting from this project, we developed this toolkit to assist RWHAP, HOPWA, and other potential partners with integrating their data systems and planning for their ensuing client service coordination.

Objectives of This Toolkit

This toolkit is designed to help organizations planning to integrate their data. It highlights critical decision points and activities that organizations interested in data integration should consider before the initiation of such a project. Because the specific details of data integration will be highly dependent on the data systems involved and the specific settings of the project, this toolkit is intended to provide high-level guidance so that the project can be completed efficiently.

What Topics Are Covered in This Toolkit?

Lessons learned from the performance sites were used to identify the following critical decision points and specify the objectives that accompany each:

- **Readiness:** Identify pre-data system integration activities (e.g., client consent, data-sharing agreements, stakeholder engagement).
- **Current service coordination deficiencies:** Identify primary challenges to client service coordination between partner organizations that could be addressed by data system integration. Strategize on how data integration would improve deficiencies.
- **Technical decisions:** Select (1) a data integration model and (2) integrated data system functionalities. These decisions should be made with partners and, in many cases, data system vendors.
- **Enhanced service or care coordination:** Determine how service or care coordination across providers (hereafter referred to simply as *service coordination*) should be handled once the data system integration is complete.
- **Training on use of integrated data system and service coordination:** Design trainings to ensure that end users gain proficiency in (1) technical aspects of the newly integrated system and (2) concrete steps for using the new information to enhance service coordination.
- **Quality measurement:** Ensure that providers are using the integrated data system and implementing strategies to improve service coordination.

What Is Contained in This Toolkit?

The toolkit contains guidance that will walk organizations through each of the topics above and highlight key questions, options, and critical activities to successfully complete the goals of a data integration project. For each of the key questions/decision points, we include a checkbox to mark as questions are answered. Below each question, we also include space to fill in answers relevant to an organization. Lessons learned by those at the performance sites who participated in the *Addressing HIV Care and Housing Coordination Through Data Integration to Improve Health Outcomes Along the HIV Care Continuum* project are also offered where relevant.

Who Should Use This Toolkit?

The primary audience for this toolkit is organizational leaders from RWHAP, HOPWA, and other organizations that serve people with HIV and are interested in data integration and want to learn more about it before proceeding. The toolkit is also relevant for policymakers and city or jurisdictional leadership. Even if funding for such a project is not yet finalized, there are various preparatory activities that organizational leaders can complete.

2. Readiness

Goals for This Chapter

This chapter is designed to help you

- understand the current client consent process for sharing data across providers
- determine what data that clients at participating organizations have already consented to share
- decide what changes to client consent need to be implemented for optimal data integration
- learn about who in the organizations should prepare a data-sharing agreement, what needs to be included in the agreement, who should sign the agreement, and how the agreement should change over time
- determine which organizations and individuals are key stakeholders for data integration and how to engage them in the planning and implementation process.

Client Consent for Data-Sharing

Clients who have data maintained by an RWHAP provider in a database (e.g., CAREWare, electronic medical records) should have been asked by the RWHAP provider organization for written consent to share their data—including medical data—with other providers. Similarly, HOPWA and many other programs require written client permission to share information with other entities. The Health Insurance Portability and Accountability Act (HIPAA) governs the exchange of certain types of personal information, including medical data. HIPAA legislation requires that specific data privacy and security provisions be followed in the exchange of individuals' medical information, including consent to share information. If you integrate your data system with another provider organization to share client data, your organization will need to collect written consent from clients to share their data with those additional providers.

Questions to Ask Yourself

- What exactly does it say in our client consent form now?

What model of client consent do we have? Is it a blanket consent in which clients agree to having their data shared with providers from relevant organizations so long as data-sharing agreements are in place? Or is it a point-to-point consent model in which clients need to be re-consented each time a new provider organization signs a data-sharing agreement?

Should we change the client consent model we currently have to facilitate better data-sharing? What would that entail?

Lessons Learned

The following are some critical lessons learned by those at the performance sites on client consent.

- An approach that uses **blanket (rather than point-to-point) consent is easier to manage** in the context of data-sharing with multiple organizations.
- **It can take a great deal of time to re-consent all clients when new data-sharing agreements are enacted.** Clients often have to wait until they next see their providers in person to do this task.
- **Clients are important stakeholders in the process of data integration and should be consulted in the process of developing consent forms.** Some clients may not feel comfortable sharing their data with other provider organizations because of previous poor experiences that cause a lack of trust.
- **To engage clients and garner buy-in, explain to clients the potential benefits of data integration,** which include less paperwork, more provider time spent delivering services to the client, and more timely follow-up from providers, among others.
- **Consent documents should be revisited regularly with clients** so they fully understand with whom their data are being shared, what types of data are shared, and for what purpose.

For a sample consent document adapted from the *Addressing HIV Care and Housing Coordination Through Data Integration to Improve Health Outcomes Along the HIV Care Continuum* project, see the appendix.

Data-Sharing Agreements

Each provider organization that wishes to contribute data to the integrated data system will need to have a signed data-sharing agreement in place with other data-sharing organizations. The agreement will specify important aspects of the data-sharing between two (or more) providers, including what client data elements will be shared, data-sharing frequency, and the data security measures and responsibilities of each organization. To enact the stipulations of the data-sharing agreements, it is crucial that data system vendors participate in this process and understand what technical changes will need to be made to meet the agreed-upon stipulations.

Questions to Ask Yourself

Have we ever shared data with another organization before? If yes, how did we do it? Do we have a template from that effort we could adapt?

Who at our organization should lead the writing of a data-sharing agreement? Who needs to review the language to ensure it meets legal requirements?

Who at each participating organization needs to sign (authorize) the data-sharing agreement?

What role should our data system vendor play in the data-sharing agreement? What changes will need to be made to the data system to implement the data-sharing agreement?

Lessons Learned

The following are some critical lessons learned by those at the performance sites on data-sharing agreements:

- Even if not all funds are in place to complete the data integration, **it is wise to begin working on the data-sharing agreement as early as possible**. The agreement, and all the authorizing signatures, will take a long time to put in place.
- **Involve lawyers and contract administrators early in the process of creating data-sharing agreements**; they are the people who typically address such issues as data-sharing and can provide early feedback on language to save time later in the process. Lawyers can also help understand/navigate any state and local laws around data-sharing outside of HIPAA, RWHPA, and HOPWA confidentiality requirements.

Securing Stakeholder Buy-In and Engagement

It is crucial to engage various stakeholders early in the process to build and maintain support for your data integration efforts. Consulting with organizational leadership, front-line staff who will use the newly integrated system, and clients can help you understand pain points in your current service coordination processes and make important design decisions to resolve these challenges. Engaging stakeholders also gives you a chance to demonstrate early on why this project will be useful and develop champions who can help you maintain buy-in throughout your data integration process.

Questions to Ask Yourself

How can we tell the story of data integration in a way that resonates with our stakeholders and creates buy-in?

From which organizational leaders do we need support to ensure success? Who can make the relevant decisions about financing, data-sharing, etc.?

Who might serve as a champion for the process and help us generate buy-in among providers who will ultimately use the integrated system?

How can we reach stakeholder organizations with messages about our data integration efforts?

What are the competing priorities among our stakeholder groups and how can we address those?

Lessons Learned

The following are some critical lessons learned by those at the performance sites on creating stakeholder engagement.

- When trying to **generate stakeholder buy-in, tell a story or provide case examples that emphasize the practical outcomes** (fewer papers to bring back and forth to appointments, better communication among providers, better outcomes for clients) rather than the technical specifications of data integration and outcomes that may not resonate as well with your audience.
- **Use a variety of mechanisms to inform stakeholders of plans for integration** (e.g., existing councils and community meetings and integration-specific convenings). Use these same venues to allow stakeholders to provide input into the process early on—both on desired system functionality and on processes for service coordination.
- Create feedback loops and **frequently keep stakeholders up to date on project activities** and progress.
- **Allow users from all integrating organizations to test the system multiple times** and give feedback before launching.

3. Current Service Coordination Deficiencies

Goals for This Chapter

This chapter is designed to help you

- identify the current state of client service coordination across one or more partner organizations serving the same population
- specify the areas in which performance on coordination requires improvement through the engagement of organizational leadership, providers, and clients
- strategically make choices about data-sharing with partner organizations to improve service coordination.

Current State of Client Service Coordination

Data integration should be undertaken with the intent of (1) making experiences better for clients; (2) improving client health, housing, and/or services outcomes; and (3) streamlining processes for providers so that they can spend more time providing services and less time doing paperwork or tracking down important information. One of the first steps is to ask providers and clients about exactly what problems exist (for example, with coordination, communication, access to critical client data, eligibility processes). It is important to gather information from various provider staff who serve different roles (e.g., intake/eligibility workers, case managers, data managers, etc.) to identify as many opportunities for improvement as possible. Once the challenges are identified, you can select a data system integration approach and system functionalities to address those issues directly.

Questions to Ask Yourself

How is current service coordination conducted for existing joint clients across our programs?

How do we conduct referrals for clients with new service needs?

What specific areas of coordination are inefficient and time-consuming for providers?

What kind of solutions do providers think would improve service coordination?

What kinds of client information do providers frequently need but either do not have access to or have to work hard to obtain, and why?

How do clients feel about the coordination of services they receive now?

What are the potential benefits of an integrated data system? Potential drawbacks?

What are provider concerns about using an integrated data system? Client concerns?

Lessons Learned

The following are some critical lessons learned by those at the performance sites on current client coordination deficiencies.

- **There are many ways to solicit information from both provider staff and clients about the challenges to service coordination.** For example, consumer advisory board meetings can be used to ask clients about what they see as critical issues. Questions about challenges can also be included in needs assessments or consumer surveys. Portions of standing staff meetings or cross-organization community meetings can be used to solicit provider feedback (either through surveys or a discussion).
- **Providers across different programs are often unaware of each other's roles and responsibilities.** They aren't sure what services their counterpart providers offer or under what limitations they operate. This can sometimes lead to one provider asking their counterpart for client services that the counterpart is unable to provide.
- **Communication across providers from different programs is often inconsistent or unprioritized.** Providers might only communicate with each other when a joint client has an emergency or experiences a crisis (e.g., upcoming eviction hearing is scheduled).
- **Provider concerns about using a new integrated data system include added workload associated with training and doubts about the day-to-day utility of information that will be shared.**
- **Providers often spend a great deal of time hunting down critical client information** by trying to figure out which other providers might have this information. This entails tracking down the contact information for the other providers, making phone calls to other providers, and waiting for return calls.

4. Technical Decisions

Goals for This Chapter

This chapter is designed to help you

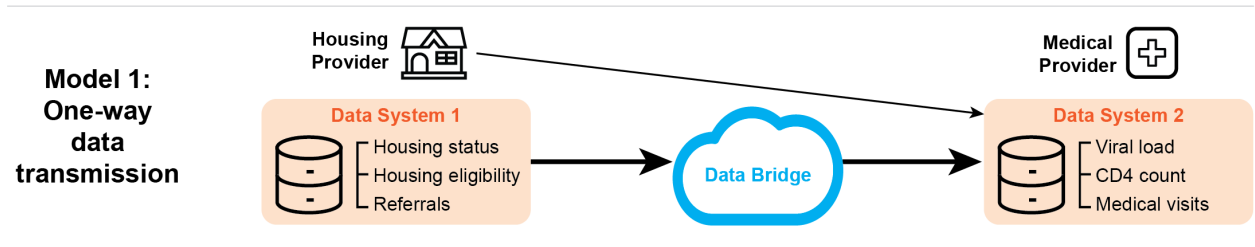
- choose a data integration model that is feasible for all partner organizations and maximizes efficiencies
- select integrated data system functionalities based on identified service coordination deficiencies
- determine the changes that data system vendors would need to make to integrate two or more data systems, how they would implement new functionalities, and what timelines and costs would be involved.

Data Integration Models

In this chapter, we describe three data integration models. Although this is not the universe of data integration models, these three options cover most of the fundamental technical decisions that need to be made. In the following examples, we describe the integration of data systems across two partner organizations only (recognizing there could be more). Our examples propose data system integration across a housing partner and a medical provider. For that reason, the examples of data elements to be shared (e.g., housing status, viral load) are relevant to housing and medical services. You may be interested in integrating data from different social or human services providers. Although the specific data elements to be shared may differ, these general models will still apply.

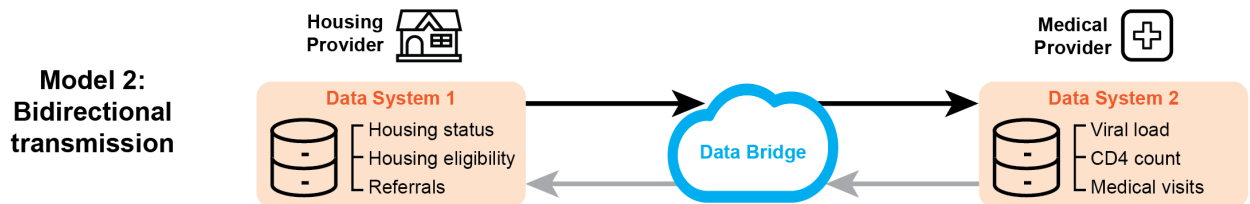
Under Model 1, housing and medical providers use and maintain separate data systems. Data-sharing occurs through a one-way data bridge. In Figure 4.1, the data bridge shares selected housing variables from the housing provider system to the medical provider system only. The data bridge can be activated at a frequency agreed upon by both sides (e.g., daily or weekly updates). Medical providers can see housing information for their clients in their own data system. However, housing providers require access to the medical provider's system to see medical information, with the result that housing providers might encounter some inefficiencies (accessing shared data through a separate system). Therefore, this model may be selected if one partner experiences administrative barriers to data-sharing or if one of the partners has existing access to both systems.

Figure 4.1. Model 1: One-Way Data Transmission



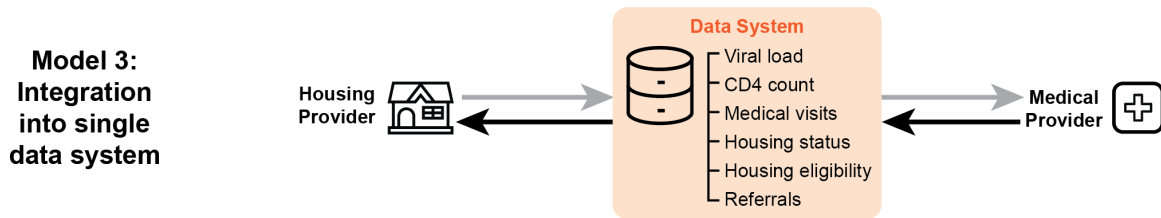
In Model 2, both systems share client data with each other using a two-way data bridge, or bidirectional transmission (see Figure 4.2). In this scenario, medical providers and housing providers continue to access only their existing data systems to see new shared client data. Model 2 provides some efficiencies over Model 1, in that neither type of provider needs special access or training to use a different system, although training is needed to access and interpret new data elements and understand service coordination protocols. Model 2 also requires intensive coordination across data vendors of the two systems to ensure clear understanding of what information will be shared, where it will be mapped to in the companion system, and troubleshooting of any possible technical issues.

Figure 4.2. Model 2: Bidirectional Transmission



Model 3 has the highest level of efficiency for both housing and medical providers, because they both use one system containing all relevant client data (see Figure 4.3). Updates are accessible to all providers in real time, unlike the other models, in which client data are updated at agreed-upon intervals. Although Model 3 is the most efficient, it is not always feasible. Programs with existing data systems would need to make significant logistical changes to transfer client data to a new system, including potential disruption of workflow as providers transition to the new system. In addition, the shared single system may not meet the data needs for all clients in an organization, requiring providers to understand and use two different systems (i.e., one for clients shared between a housing and medical provider and one for all other clients).

Figure 4.3. Model 3: Integration Into Single Data System



Questions to Ask Yourself

What data systems do we and our partner organizations currently use?

Do all of our partner organizations maintain a client data system, or are one or more organizations working from paper files?

Are any partner organizations dissatisfied with their current client data system and thus potentially willing to change to a different system?

What challenges might we encounter when switching from one data system or data vendor to another?

Lessons Learned

The following are some critical lessons learned by those at the performance sites selecting data integration models.

- **Even though the most efficient integration model allows all partner organizations to use the same data system, it is not often the most feasible** because it would require new funding and/or the wholesale transfer of one or more provider's existing data into a new system.
- If you would like to transition to a new data system and vendor (either to streamline to one shared data system or to select a system more amenable to data-sharing), **it is important to understand the current contractual agreement with the existing data vendor** as you make decisions to transition. Data systems are often a dedicated line item on operational budgets and change may be difficult once budgets are approved.
- Providers are critical to keeping the integrated data system useful because they need to enter the client data in a timely fashion. An integrated data system is only as useful as the accuracy of the information it contains. **To enhance accuracy, it is important to ensure that providers believe the information they are entering is valuable and useful.**
- **If the model you are considering requires providers to enter the same data into two different systems or access systems that are not currently part of their workflows, you will need to assess the feasibility of these activities and generate new workflows to accommodate them.**

Integrated Data System Functionalities

Although there are many integrated data system functionalities from which to choose, here we focus on those that can support improved service coordination. Having an integrated data system does not, on its own, automate coordination, but it can streamline many manual processes. After integration, providers will still be engaging each other in coordination, ideally in a manner that is more meaningful to the client because of systematized information-sharing and a reduction in paperwork.

Flags/Alerts

Data systems can be programmed to “flag” data. Flags that can be used to enhance client service coordination include, for example, if specific client data fields (e.g., housing status) have not been updated over a certain period of time, if a client appears to have fallen out of care, or if a client's viral load becomes detectable. Including flags and alerts about out-of-date information or upcoming milestone dates (e.g., rent renewals) gives all providers a better understanding of the client's situation and provides additional opportunities for providers to offer support (e.g., if a housing provider notices an out-of-care flag, she can talk to the client about this and coordinate with her counterpart provider to ensure that the client can schedule an appointment).

Secure Direct Messaging

One way to enhance service coordination is to facilitate communication between providers. Nonsecure email cannot be used to share client data across providers. However, an integrated data system can be equipped with secure email or messaging between providers that complies with privacy and security rules, such as HIPAA. For this functionality to work, it is essential for clients to be assigned or affiliated with case managers/providers in the system so that the direct message reaches the correct person in the counterpart agency.

Shared Reports

Client-level shared reports between organizations can help providers identify clients with priority issues and better coordinate service plans and program recertification documentation. Shared reports are also useful at the organizational level, such as summary performance measures across all joint clients to identify broader challenges.

Shared Provider Contact Lists

Often, the names and contact information for all providers serving a client are not available to each individual provider. An integrated data system is an ideal place for providers to enter their information and affiliate it with clients on their caseload so that counterpart providers spend less time tracking down this information.

Link Clients to Providers

If every client is linked to a case manager or other provider in the system, other users will know whom to contact for any issues regarding this client. If or when a new case manager takes over, keeping this information updated in the system would eliminate confusion and lags in communication.

Questions to Ask Yourself

What specific areas of coordination do both providers and clients want improved and how can we implement new functionalities to address those areas?

In what specific ways will our proposed new functionalities support service coordination?

What is the new step-by-step process that our providers will need to follow to maximize the new functionalities' benefits?

What are the barriers to providers using the new functionalities and how do we address them?

How can we best message to providers the benefits of using the new functionalities?

Lessons Learned

The following are some critical lessons learned by those at the performance sites selecting integrated data system functionalities.

- **Buy-in from providers is critical to getting them to use the new functionalities.** Allowing providers to suggest functionalities and test them out before launching can greatly increase their engagement with the integrated system.
- **Such functionalities as shared reports across partner organizations can be influential** for planning but require a higher level of organizational coordination and commitment.
- **Training for use of new functionalities cannot be a one-time activity.** Follow-up training is essential to identify where providers have continued gaps in knowledge.

Engaging Data System Vendors

A data system vendor is typically an external company that is paid to set up and maintain data systems. Data system vendors¹ must be invested and involved in this venture because they will likely be the ones to translate your ideas into the technical work needed to integrate and enhance the data system. In some cases, your own internal IT department may be able to make the necessary changes to a data system to facilitate integration. However, your partners in data integration may still require the engagement of a data system vendor.

Organizations may find themselves hesitant to launch a project like data integration because, even though they understand the benefits, they do not feel well-versed enough in their data management systems to make all of the technical decisions. If you have a good relationship with your data vendor, they may be able to serve as guides through the process. If you would like additional support, you can hire a consultant who can help translate your integrated data system needs into a plan for the vendors. Vendors may discuss different issues with you as they effect data integration (e.g., a roadmap or plan for the data system integration, software update schedules for the data systems, changes to your existing system that could improve data integration for service coordination, new functions for users in upcoming software versions, how best to coordinate the technical exchange of data from a software point of view).

¹ For the purposes of this toolkit, we define a *data system vendor* as a third-party organization who services your data system, providing updates and upgrades as they become available. Vendors could provide an array of other services, such as performing routine maintenance, troubleshooting problems with the software, customizing functionality and reports, and providing training to new users, among others.

Questions to Ask Yourself

Is our internal IT department well versed enough in our data management system to provide some or total support to data integration? If yes, what support can they provide?

Do we have a data system vendor? If so, what kind of support are they currently contracted to provide?

What is the payment structure between our organization and the vendor? Do we pay the vendor each time for a data or report request or is maintenance and reporting built into the contract?

What is the timeline that the data vendor(s) can agree to for carrying out the work, including training for our users, key milestones for the project as we have defined them, and testing by our users?

Are there any major barriers that could derail the timeline, such as major upgrades to the data system software that may be required or be beneficial for supporting the integration between our system and another one?

Are there barriers to multiple data system vendors working together to complete the project?

How do our contracts with vendors need to change to maintain the integrated data system?

What is our communication and accountability plan to keep vendors on track to complete the integration?

Lessons Learned

The following are some critical lessons learned by those the performance sites working with vendors.

- Even the best-coordinated plans can be delayed by unforeseen issues related to data vendors. **It is critical to ask vendor representatives about planned major software upgrades by their companies or any other changes that might cause delays.** Once integration projects have started, monthslong vendor-related delays can cause the process to lose momentum or buy-in.

- **It is critical to understand up front how the contract with the vendor is structured to avoid unforeseen costs later on in the project,** particularly maintenance costs for updating and revising systems on a continuous basis. This is one reason to consider engaging a consultant to help guide the technical work if your organization lacks expertise.

If you are working with multiple vendors, it is helpful to have a knowledgeable data manager from one of the provider organizations serving as a project manager. This individual can clearly communicate expectations to all vendors, make sure the vendor-led work is being done correctly and on the agreed-upon timeline, and share progress and any challenges with all participating organizations to reach resolution.

5. Enhanced Service Coordination

Goals for This Chapter

This chapter is designed to help you

- define expectations for how providers will use the new client-level data accessed through the integrated system
- specify the service coordination processes that providers will be expected to participate in based on the integrated data system
- identify additional needs and opportunities to coordinate at the organizational and provider levels based on new shared data.

New Mechanisms of Service Coordination

Simply having access to new client data will not automatically improve coordination. Providers need to understand how to interpret the new client data they are seeing and have a shared understanding of how all providers will respond to the new data. For example, if a provider at a housing agency sees that a client is out of care, what is the protocol for coordination with that client's medical case manager? The housing provider has an opportunity to get a client back into care but needs to know whom to call and what the hand-off process should be. Not spending the time to specify and train providers on these mechanisms might lead to missed opportunities and inefficient use of your investment.

Questions to Ask Yourself

What supports do providers across our organizations need to develop a shared understanding with regard to service coordination processes and responsibilities? Do providers need joint trainings? Are there clear flow charts documenting new coordination pathways?

For each new client data element shared and new integrated data system functionality implemented, what are the service coordination mechanisms that should be enacted?

What is the best way to use the new integrated data system to improve communication between providers across our programs?

What are the frustrations our clients experience in having multiple providers? How can we use new information and new service coordination mechanisms to address these frustrations?

Lessons Learned

The following are some critical lessons learned by those at the performance sites implementing new service coordination mechanisms.

- Providers from different programs have different roles, responsibilities, and resource constraints. **Learning about the jobs of other providers is a critical first step to developing new coordination mechanisms.** Include a discussion of terminology used because providers in different systems often use different language when referring to the same or similar things.
- Coordination for existing joint/shared clients will likely look different from that for new clients. **Think about what these new referral processes for joint clients should look like and what role each provider organization will have.**
- If providers would like to share additional client information to decrease time spent on conducting program eligibility, they should carefully review eligibility requirements across programs to find similarities and differences. **Prompt entry of client information by all providers is especially important for the eligibility process.**

Opportunities to Coordinate at the Organizational Level

It is quite possible that your partnering organizations will not have established close relationships with each other prior to the project. However, improving service coordination at the provider level cannot happen efficiently without organizational coordination and information-sharing.

Questions to Ask Yourself

- How can we work better with partnering organizations offline (i.e., outside of the shared system) to ensure success of ongoing client data-sharing?

- How can we best support our providers and encourage them to work more closely with their counterparts at partnering organizations?

Lessons Learned

The following are some critical lessons learned by those at the performance sites about opportunities to coordinate at the organizational and provider levels.

- **Establishing regular organizational communication (e.g., through standing calls or meetings) is vital** and can help ensure that partnering organizations have a shared understanding and can then communicate the same messages to their provider staff and use the same processes to translate new information into better client services.
- **Joint trainings are critical opportunities to bring providers from different organizations together** to build relationships, develop a shared understanding of roles and responsibilities, and generate solutions to shared challenges.
- **Ensuring that providers have time and support for provider-initiated meetings and a shared set of client information from which to work can improve coordination efforts.**

6. Training on Use of Integrated Data System and Service Coordination

Goals for This Chapter

This chapter is designed to help you

- determine what technical training providers will need to perform new data entry, access new data entered by counterpart providers, and use new functionalities (e.g., flags, alerts, reports)
- identify training needs related to new and improved processes for service coordination
- determine what ongoing training support is needed, including training needs for newly hired staff.

Technical Trainings

Depending on what model of integration you choose, some providers may be using a completely new system. Training for these providers will require extra effort and time; it is important to anticipate these needs and build them into your project timeline. Even if providers will be using a familiar system, they will need to look in new places, enter new information, and/or understand new functionality.

Questions to Ask Yourself

How familiar are our providers with basic functions of the integrated data system? Are they learning a completely new system or will they only need training on how to use specific new features in a system with which they are already comfortable?

Within each of our partnering organizations, will individual training needs change depending on role?

How will we assess knowledge/skills gained during trainings?

How often do we need to do refresher trainings? How will we handle new staff who are hired between training cycles?

Lessons Learned

The following are some critical lessons learned by those at the performance sites about technical trainings.

- **Trainings are most effective when providers have multiple formats for learning,** including opportunities for hands-on learning with actual data (e.g., giving providers a fictitious client and asking them to find or enter data about this client), screen share components to support visual learners, and trainings that are recorded and posted for later reference. Recorded trainings can also be used to successfully train newly hired staff.
- **It can be helpful to have overall training for all provider roles coupled with specific, shorter trainings based on what an information provider will use most.**
- **Developing short manuals or “cheat sheets” for most-used information can facilitate effective provider use of the system.**
- It is important to understand how confident providers feel using the new system and to check how well new data and functionality are being entered and used after training is completed. **Be prepared that the training period may take longer than anticipated and some providers may need multiple training sessions to feel comfortable** using new systems/new information.

Service Coordination Trainings

Although technical trainings are certainly critical, they are only as effective as the service coordination trainings that accompany them. If providers do not understand how to work with each other and use the new information available to them to enhance client services and outcomes, your data integration efforts might fall short of desired outcomes. Ensuring that providers understand the importance of new information and new workflows and how these

changes should be integrated into their day-to-day activities is one of the most critical parts of a data integration project.

Questions to Ask Yourself

What terms should we use to identify and define new and important information?

What training do providers need to understand how each organization's services contribute to overall client well-being?

How can we best train providers on workflow changes?

How will we monitor whether service coordination efforts are taking place?

Lessons Learned

The following are some critical lessons learned by those at the performance sites about service coordination training.

- **Before effective service coordination can occur, it may be necessary to clarify definitions** for variables and terminology that will be used for service coordination across provider agencies—both within the integrated data system and in conversations across providers.
- **Joint trainings (i.e., trainings with providers from all participating organizations) can be highly effective for enhancing service coordination.** These trainings are most effective when they include case studies or real-life examples of how each piece of information in the new data system can be used to enhance service coordination across organizations.
- **Without specific trainings in service coordination, providers may not understand how they should use the new information available to them** or why they should take on additional data entry/client coordination tasks.

Ongoing Training Support

During the lead-up to and initial launch of the integrated data system, there is typically a focus on training in new system functions and how to use them. After the system launch, training funds and focus could wane. However, ongoing training can be as important as initial training to ensure the successful use of the newly integrated system. In addition to planning for these ongoing trainings, you will also want to ensure that training on the integrated system and service coordination are thoroughly integrated into the onboarding process for newly hired staff.

Questions to Ask Yourself

How often should we offer booster or refresher trainings? How will we know when they are needed?

How will we train staff on any new functionality added or new information available after initial launch of the integrated system?

How will we ensure new staff are trained on system functionalities and service coordination processes?

Lessons Learned

The following are some critical lessons learned by those at the performance sites about ongoing training support.

- **Making electronic training materials available to all providers (e.g., posting online or in a central repository that providers can access) allows them to check their understanding at any point in time** and avoids the need for calls to the in-house data manager or vendor support line. Online trainings can also be used with newly hired staff.
- **Providing cheat sheets and user manuals** that distill training information into easily digestible formats can greatly enhance ongoing use of the new system.
- Ongoing joint trainings are an effective way to continue to **build rapport across providers** and enhance coordination efforts.
- Staff turnover can be a significant challenge for provider organizations. In order to ensure the ongoing use and success of the integrated data system, **the onboarding process for new staff must include training on service coordination and use of the integrated data system.**

7. Quality Monitoring

Goals for This Chapter

This chapter is designed to help you

- determine how you will monitor provider use of the newly integrated system
- understand whether and how the newly integrated system and accompanying service coordination is positively affecting client outcomes
- understand whether and how the newly integrated system and accompanying service coordination is affecting staff workloads and ability to meet goals
- understand what changes may be needed to either system functionalities or training after initial system launch.

Monitoring System Use

Once your integration system is launched, it will be important to understand if and how providers are regularly using the new information available to them. Providers have many competing demands and may not always immediately see the benefit of entering new information into the shared system or using information newly available to them for client service coordination. However, data integration will only be successful if providers are entering shared information in a timely fashion and using the information newly available to them in their day-to-day work.

Questions to Ask Yourself

- What data do we currently collect about system use?

- What data would we need to collect to successfully monitor system use? What level of effort will it take to collect this new data?

Do we have the staff capacity to monitor system use?

What mechanisms do we have in place to encourage and enforce system use?

Lessons Learned

The following are some critical lessons learned by those at the performance sites about monitoring system use.

- **It is important to regularly monitor the frequency and the method in which providers are using the newly integrated data system.** This can be accomplished through usage reports run through the system itself or more informally by checking in with providers and asking how they are using the new system and new information.
- One way **to ensure use of the new system** is for program funders to **include it as a requirement in contracts with provider organizations.**

Understanding Impact of System Integration

Launching an integrated data system requires significant funding and staff time on the part of integrating organizations. After making such a substantial investment, you will want to know whether the availability of new information is having a positive impact on client outcomes and staff workloads. You will want to establish a few key goals and track metrics related to these goals to determine the impact of the system.

Questions to Ask Yourself

How will we define success for the newly integrated system? What will success look like for clients? For staff?

What metrics will we track to determine whether the newly integrated system is having the desired impact and outcomes?

Lessons Learned

The following are some critical lessons learned by those at the performance sites about understanding the impact of system integration.

- Being able to **articulate impacts of the integrated system is crucial to ensure ongoing provider buy-in and to secure ongoing or new funding** for the system.
- **Monitoring metrics should cover outcomes that are meaningful** for all contributing organizations (e.g., tracking medical and housing outcomes).
- Organizations can **work with the data system vendor to set up reports** that track how often providers are accessing the new client data elements.

Determining Whether Additional Changes Are Needed

Once you have determined goals for the system and established the routine collection of metrics for monitoring progress toward these goals, you can use this information to determine whether additional changes are needed. For example, you might find that staff are still missing crucial pieces of information for service coordination. Or you might find that adding additional flags or alerts could greatly enhance service coordination.

Questions to Ask Yourself

How often will we review quality monitoring data? Who will be involved in this process?

How will we solicit staff feedback to determine whether additional changes are needed?

How will we pay for added functionality if it is needed?

Lessons Learned

The following are some critical lessons learned by those at the performance sites about determining the need for additional system updates/changes.

- Providers and organizational leaders often **might not understand what kinds of functionality or information-sharing are most helpful until they begin using the integrated system** and service coordination processes.
- Ongoing, already established **provider meetings can be an excellent venue for soliciting staff feedback** on system functionality and whether additional changes could be helpful.
- **Decisions about additional system functionality should be made jointly with all organizations contributing data** to the integrated system to ensure awareness and maximize potential impact.
- If possible, it is important to **build in funding for system maintenance, technical support for unplanned problems**, and ongoing improvements into programmatic budgets.

In Closing

One of the goals of this toolkit is to demystify the process of data integration and make it more accessible to service organizations in general. Although the integration of data systems might seem challenging, it can provide substantial gains in saving provider time and improving

service coordination. By answering the questions in this guide and considering lessons learned from previous implementers of data integration, we hope you will have a better understanding of the step-by-step process of planning and implementation and gain confidence in your ability to navigate the process.

Appendix. Sample Client Consent to Share Data

Consent for the collection and sharing of client information to providers under Ryan White and Housing Opportunities for People with AIDS Programs

_____ [NAME OF AGENCY] is mandated to collect certain personal information that is entered and saved in a database system called CAREWare and/or CaseWorthy. CAREWare and CaseWorthy records are maintained in secure servers per organizational policy for security and privacy by _____ [NAME OF ENTITY] and _____ [NAME OF ENTITY] respectively. Both CAREWare and CaseWorthy aggregate reports may be used for advocacy, both statewide and federally, any client information used will be done so without revealing names or other identifying information.

The CAREWare and CaseWorthy database programs allow for certain medical and support service information to be shared among providers involved with your care. This includes but is not limited to medical visits, lab results, prescribed medications, emergency financial assistance, nutritional supplements, case management, transportation, housing, substance abuse and mental health counseling services.

You have a right to opt out of this electronic sharing. If you choose to opt out of electronic sharing it may make it more difficult to coordinate Ryan White and Housing Opportunity for People with AIDS services.

I, _____ [PRINT NAME], hereby provide my consent and authorization for _____ [NAME OF AGENCY/RYAN WHITE PROVIDER AND HOUSING OPPORTUNITY FOR PEOPLE WITH AIDS NETWORKS] to share my client-specific health, treatment, and support service information in the encrypted CAREWare and Housing Opportunities for People with AIDS database programs which is operated and maintained by the _____ [NAME OF ENTITY] and _____ [NAME OF ENTITY] respectively.

I further provide consent and authorization to allow the disclosure and sharing of the information entered into the encrypted CAREWare and CaseWorthy database programs by _____ [NAME OF AGENCY]. This information will only be shared with providers to which I consent to share my information with. I understand that these agencies that I apply for Ryan White and Housing Services may request the information for the purpose of informing and coordinating treatment and benefits I receive under the Ryan White Program and Housing Opportunity for

People with AIDS. By signing this form, I further acknowledge that if I fail to show for scheduled medical and other support appointments, I may be contacted by an authorized representative of the above-referenced agency in order to re-engage and link me back to care.

This consent will expire 18 months from the date this document is signed.

Client Signature

Date

Witness Signature

Date

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